A PATIENT MONITORING TOOL FOR AN HIV/AIDS INTEGRAL CARE MODEL

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Abstract- **The success of new therapeutic procedures based on combination of antiretroviral components is driving the need of new care models for HIV/AIDS patients. This paper addresses the definition and implementation of an HIV/AIDS integral care model grounded on medical, psychological and social patient self-monitoring procedures. The care model is implemented on a web-based monitoring tool bearing three main scenarios: self-monitoring personal diary, data analysis and visualisation of data collected and an anonymous communication tool for patients and health/social care professionals. A preliminary validation of the model and system has been accomplished under the EU SEAHORSE project to assess the system performance and usability of the self-monitoring tool. Evaluation results show a positive users acceptance and give us feedback to improve the validity of the tool and the procedures that enable a web-based model for HIV/AIDS patient care.**

Keywords - **HIV, AIDS, web, care model, chronic care**

I. INTRODUCTION

HIV/AIDS epidemic was first discovered in the 1980s and today more than 21.8 million people have died from it, and there is an estimated 36.1 million people living with HIV/AIDS in the world [1]. But the situation of the HIV infection, for those patients who tolerate or have access to the new potent combination antiretroviral treatments, is being transformed from a uniformly fatal disease into a long-term illness [2]. At the beginning the care model was merely palliative, seeing HIV/AIDS only from its clinical point of view. But now this "chronification" implies that new aspects of the disease have to be taken into account, like the psychological and social points of view.

This new scenario demands a new care model: the integral care HIV/AIDS patient care model. This is also called the biopsychosocial HIV/AIDS patient approach, bearing in mind the three aspects: medical, psychological and social [3]. Quality of life is another issue to be tackled, because the power of these drugs involves new side effects, and the newness of the treatments makes it impossible to predict the long-term effects [4].

As people living with HIV/AIDS become aware of their new health status, they have to learn how to manage their chronic disease. This new situation leads to the incorporation of the self-monitoring concept in the HIV/AIDS domain in order to improve health status and reduce hospitalisations [5].

To facilitate the adaptation to this new scenario, we developed within the SEAHORSE II European project [6], a web-based system to provide, both health professionals and patients with tools to improve the illness monitoring [7]. This paper will describe this system based on the new care model.

II. THE INTEGRAL CARE MODEL

The HIV/AIDS integral care model requires the integration of the three different aspects of the epidemic. This means collecting clinical, psychological and social data from the patients for themselves and for their health care providers [8]. This model also involves collaborative work between health professionals from different specialties, like HIV/AIDS medical doctors, GPs, nurses, psychologists, social workers, etc. The electronic patient record should be enhanced to include the psycho-social dimensions of the illness.

The base of this care model is the self-monitoring process. The HIV/AIDS patients are aware of their health situation and they have much more information than many other patients. They look for a better and more complete advise when they contact with their health care providers and they are very capable of self-monitoring their health parameters [9].

So we implemented part of this care model on a prototype web-based self-monitoring system and evaluate the results.

The use of a model approach allowed to carry out a comprehensive analysis of user requirements. The care model led to define three application scenarios to be supported by the system: the first one in which the patients carry out the self-monitoring process collecting and consulting personal and clinical data, to continuously update the patient monitoring record; the second one, that provides patients and health care professionals a set of data analysis and visualisation tools to compare and study the evolution of all those follow-up parameters based on the different therapeutic goals; and the third scenario in which the patients can ask for advising to a HIV/AIDS expert on related issues of their illness process, based on the available information on the patient record.

III. SYSTEM DESIGN

At any of these scenarios a hierarchical task analysis was performed, following a user-centred methodology [10], to specify the user interface components and structured dialogues. The usage scenario, simplicity and easy-to-use of the tool, the required universal access and interactivity, and a preliminary cost-benefit analysis were absolute priorities both in the design and further implementation of the system. On that purpose, the most suitable technical platform for developing and delivering the system that fulfil the user needs was a highly interactive web-based system [11].

The user interface of the system is fully web-based but as far as possible hides the web browser to simplify the

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Abstract

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interaction for people who are not used to computers. The appearance of a folder with different tags, using a real-world metaphor has been selected to increase system usability.

A. Self-monitoring personal diary

The self-monitoring process implies to register a set of health status data that conforms the patient monitoring record: Personal, Clinical, Life style and Treatment data.

Fig. 1 shows an example of the self-monitoring process user interface, in this case for the 'Life style' data:

In this particular tag, the user can see his/her feelings (psychosocial data) moving through the dates, just selecting them. If the user wants to add new data, clicking on the 'Add new Life Style data' will get him/her to a form with a free text box into which the feelings can be exposed as a diary. The tobacco, alcohol and drug profiles are just to note the situation of the user at that moment. The bars on the right are used to enter some standardised fields on quality of life. The user moves the mouse up the bar, like a thermometer, until he/she reaches the point at which he/she believes him/herself to be at that moment. This process should be repeated from time to time so the user can see the evolution of his/her lifestyle.

It is important to note that a very strong design effort was made to preserve the appearance of the visualisation form in the input form in order to make the users' learning process easier.

Clinical data is collected and visualised in the Clinical and Treatment tags. In the first one, the patient fills up some fields about the level of the immune system (CD4) and the viral load (VL), as well as the opportunistic infections the patient has had during the infection (with starting and finishing dates and days being hospitalised). It is recommended that the patient has the complete medical record to fill out all these data, although HIV/AIDS patients are very concern of their illness and they usually know all the data.
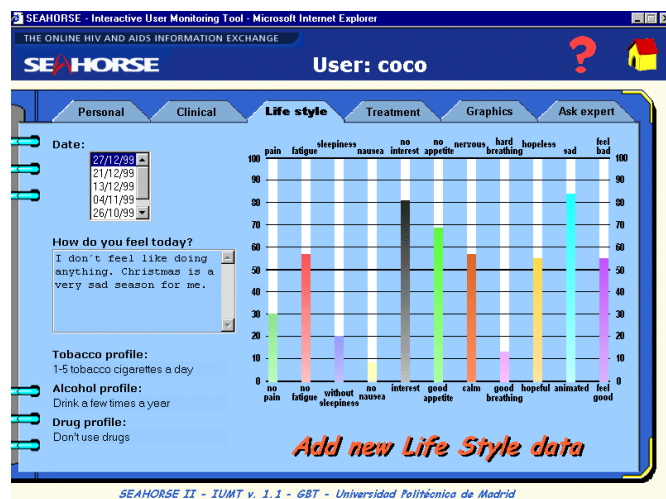
The 'Treatment' tag is one of the most complex, as the user has to enter the treatment evolution through the time he/she has been treated. The patient enters data referring to antiretroviral or other infections drugs, and to complementary therapies (like yoga, acupuncture, vitamins, herbs, …). To evaluate the adherence to that therapy, short and simple questions are used, as for example "do I have any problem with taking this drug?", "how many times last week did I miss a dose?", "when I don't take this drug, this is usually because of… oblivion, timetable difficulty, afraid of side effects, holiday or weekend, confused doctor instructions, ...". The goal is to get an independent self-monitoring record of every therapy annotating the changes of doses, adherence, side effects and subjective benefit.

B. Data analysis and visualisation

In this module the user can visualise all the parameters introduced previously in order to study the evolution of the infection and the impact the different therapies have on it with the possibility of over striking all the parameters in the same graph. An example showing the features of this function is displayed in fig. 2: the visualisation of the impact that a certain therapy has on the viral load or on the defence level.

Clicking on the boxes that appear in the upper part of the screen will represent the parameters selected by the user. Another menu will appear with all the therapies the user has had through the whole of the infection's life, and from them the user selects those that will be represented according to the following notation: a vertical line will note the start and end of a therapy and in between them, the line will represent the compliance the user had on that particular treatment. This adherence representation helps the user to see the real impact of the treatment on the parameters shown. If the adherence is low on a particular drug, it cannot influence the parameters as much as it could if the compliance was high. If there is no end line (as the second time the user of the example, 'coco', took Epivir) it means that the therapy is still being taken. We can

Fig. 1. Self-monitoring the psychosocial ('Life style') data of the patient
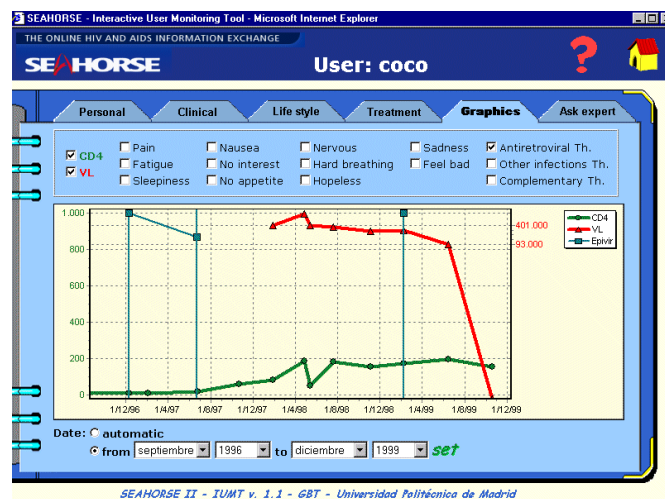

Fig. 2. Visualising the impact of a therapy on clinical parameters

see in the example of fig. 2 with real data, that the second time 'coco' took Epivir the viral load (VL) dropped to undetectable levels in eight months time and that this drug has a real impact on the parameter because the adherence to it has been kept high.

The user can also use the zoom or decide the timeline range in order to see the details of the graphic. Compliance and all the life style data will use the left vertical axis (from 0 to 1.000) as a reference, although these values are from 0 to 100.

C. Communication with expert utility

Communication with the expert is provided to the patient for him to make any consultation or ask any question. This means that a group of experts, having all the data on the screen collected by the patient, could advise and help with the questions the patient has.

The main advantages this system of ask-an-expert has over conventional e-mail system are the complete anonymity (there is no name or email address) and the personalisation of the answer is much better. The experts that usually respond to these questions on the Internet tend to give vague or too general advice as they do not have sufficient knowledge of the patient's situation [12]. By visualising the patient data, the expert can make more specific answers as well as evaluating the effect that different therapeutic strategies have on different people living with HIV/AIDS.

It is important to notice that under this care model the expert could also be a psychologist or a social worker, not just a physician, as people living with HIV/AIDS have a lot of questions on these issues too.

The expert enters the system with his/her own alias and password and will get to a first screen with a list of all the users that asked a question which has not yet been answered. It is important to note that the expert will access only the data of those patients with unanswered questions. The expert can then move through the whole selected user's data freely and see the questions to answer in the 'Ask expert' tag, where it can be replied easily from a form.

This functionality is very similar to the e-mail service: every message has the date, a subject and a body. There is a list showing the messages sent where we included a flag '®' to indicate to the patient that the message had already been answered. If the message is red, that means that it has not been read yet. The patient can write a new message, view an old one or delete any of the listed. There is no need of addresses as here the message posted by the patient is stored in the database awaiting the reply of an expert. And when this happens, the answer is also stored in the database until the patient enters the system again and reads it.

IV. SYSTEM VALIDATION

A preliminary evaluation has been carried out in order to assess the system performance and usability.

The evaluation was carried out by subjective methods based on two questionnaires completed by thirty seven users.

Questions achieved aspects like personal data, knowledge of HIV/AIDS issues, health status, usage of the system and rating of its services. Furthermore, we also used a direct observation evaluation method for the users and focus groups for patients and professionals separately.

This preliminary evaluation has provided some encouraging results. Users felt that the tool was valuable and that it could provide a useful guide to managing unpredictable and rapidly changing circumstances. It was also agreed that it was easy to use and the graphics could be easily understood. The feedback provided by the system, even with limited inputs, shows a clear picture of the effects of different interventions. Service users also felt that they were in greater control of their situation and could recognise which interventions had assisted in promoting or maintaining their health.

V. DISCUSSION

There are many issues to be taken into account in the development of a web-based self-monitoring system for people living with HIV/AIDS.

First of all, being a web-based system involves universal access to it. This has pros and cons as the wider access implies lower security and, as we are dealing with clinical data which are very sensible, the security issue was one of the most important in the development of the system. First solution was not to include the name, address, telephone number or even e-mail address in the system. This solves the problem of anonymity and the security was then taken to the already solved field of mere access to pages without permission.

There is another interesting issue about the users group of the system. As this system was created to be implemented within an European project, the cultural and social divergences of the users had to be taken into account. For example, in Spain there is a very different HIV/AIDS patients profile (most of them are intravenous drug users) than the rest of the EU. Furthermore, patients and health professionals want to monitor different parameters depending on the "country profile". For example, in England complementary therapies are used more frequently than in other countries, so users are more interested in this aspect of the system.

Finally the Spanish profile shows poor computer awareness, so the easy-to-use quality of the system is really crucial in this country. Feedback from users from the evaluation results indicate that the system interface is comprehensive enough and easy-to-use.

The socio-economic profile of the user and the country also influences the implementation, as access to Internet is not as universal as pretended.

VI. CONCLUSION

This paper has addressed the definition of an integral HIV/AIDS care model and its implementation and evaluation

on a web-based self-monitoring system for people living with HIV/AIDS and their health professionals.

The SEAHORSE European project has been a perfect framework for this development because it gave us the opportunity of getting requirements from a larger number of users and making the evaluation in three different scenarios.

The system evaluation is providing an in depth knowledge of the parameters the system monitors and the way the users interact with the tool, to continue our work on providing new models for HIV/AIDS patient care.

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